

Health Stones 4

UK Health and Learning Disability Network

For information, queries and to contribute to FPLD *health stones* contact Janet Cobb

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Please find attached the **fourth** edition of Health Stones

1. Myotonic dystrophy

I wondered if anyone on the network could recommend some easy read information on myotonic dystrophy?

Steve.Hardy@oxleas.nhs.uk

2. Involving family carers in service development

Does anyone have any examples of policies or protocols that services have developed for involving family carers in service development, and for supporting family carers whose relative is receiving a service?

Sue.Turner@ndti.org.uk

3. Protocol for an acute hospital for patient with Autism Spectrum Conditions

I am developing a Protocol for an acute hospital for patient with Autism Spectrum Conditions.

Has anyone seen anything anywhere or has any one developed anything I can look at?

Daniella Rubio-Mayer

Acute Liaison Nurse Manager

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Answer

Hi Daniella

See

<http://www.ldhealthnetwork.org.uk/docs/ldst.pdf>

<http://www.ldhealthnetwork.org.uk/docs/apoc.pdf>

<http://www.ldhealthnetwork.org.uk/docs/eoe.pdf>

& <http://www.autism.org.uk/working-with/health/patients-with-autism-spectrum-disorders-guidance-for-health-professionals.aspx>

Janet

4. LD Transition project

I recently attended a meeting regarding the setting up of a new LD Transition project. Funding for the project is for a Nurse to work with children with a learning disability with complex health needs and their transition into adult services.

Complex Health is a wide ranging remit and covers physical and emotional health needs. The Nurse will liaise with local GP practices regarding the setting up of registers from age 14. They will work autonomously and will liaise and link in with schools, adult LD teams, Paediatricians, specialist paediatric nurses etc etc.

The setting up of the project is in its initial stages.

If anyone is working on something similar I would welcome a response.

Many thanks.



Charlotte Simmonds
Learning Disability Nurse Specialist
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5. RCGP urges GPs to prepare for 'vital' expansion of learning disabilities DES

GPs should begin organising how they will provide additional health checks to thousands of young people under an expansion of the learning disabilities DES set to be rolled out within weeks, the RCGP has said.

<http://www.rcgp.org.uk/news/2014/march/annual-health-checks-for-young-people-with-learning-disabilities-are-vital-says-rcgp.aspx>

<http://www.rcgp.org.uk/clinical-and-research/clinical-resources/learning-disabilities.aspx>

6. GENERAL MEDICAL SERVICES CONTRACT 2014/15 GUIDANCE AND AUDIT REQUIREMENTS

<http://www.ldhealthnetwork.org.uk/docs/gmscg.pdf>

Pages 31-39 relate to Learning disabilities health check scheme

7. Progress on improving nursing for people with learning disabilities

<https://www.gov.uk/government/publications/progress-on-improving-nursing-for-people-with-learning-disabilities>

8. Do not attempt cardiopulmonary resuscitation (DNACPR)

A free booklet by Blackpool Teaching Hospitals NHS Foundation Trust. This is the link to the page holding the document [www.easyhealth.org.uk/listing/dying-\(leaflets\)](http://www.easyhealth.org.uk/listing/dying-(leaflets))

This is the direct link

www.easyhealth.org.uk/sites/default/files/null/DNACPR%20booklet.pdf

9. FPLD Growing Older: Improving support for people with learning disabilities: an Evaluation Toolkit for support providers to evaluate and improve how they respond to people's changing needs.

Like the population in general, people with learning disabilities are living longer; this is good news but raises questions about how will commissioners and support providers ensure that the right support is available. The Foundation for People with Learning Disabilities has been working with the Association for Real Change to encourage support providers to develop the knowledge, skills and values to respond to people's changing needs as they grow older so that their lives are as happy, healthy and fulfilling as possible.

The Foundation has developed an Evaluation Toolkit for support providers to assess how well they are currently doing and to introduce changes to improve the quality of life for people with learning disabilities as they grow older. The toolkit uses 8 person-centred outcomes (from the Association for Real Change's Challenge written by Cally Ward), such as 'I feel safe and secure in my own home', 'I am still doing the activities that are important to me, and trying new things if I want to' and 'I am well supported when the people who are important to me move away or die'.

Each outcomes has approximately six indicators of best practice against which a whole organisation, a specific service or even 1:1 support can be assessed. It is structured so that this assessment leads to the development and delivery of an action plan to improve the support that is provided. For each outcome there are also suggested resources to help organisations achieve best practice.

The Foundation is suggesting that people with learning disabilities, their families and friends should be involved throughout this process of self-assessment and action planning. They should also be able to contribute to making necessary changes, for example, through delivering training to managers and staff.

The Toolkit and Challenge can be accessed at

<http://www.learningdisabilities.org.uk/our-work/changing-service-delivery/improving-support-older/>

For further information please contact Christine Towers ctowers@fpld.org.uk

10. The Royal College of Ophthalmologists - Quality Standards for Services for Patients with Learning Disabilities

<http://www.rcophth.ac.uk/page.asp?section=444§ionTitle=Quality+Standards>

11. South West acute hospital review – learning disabilities

<http://www.swacutehospitalreview4ld.org.uk/>

12. Welcome to Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. Siblings have a lifelong need for information, they often experience social and emotional isolation, and have to cope with difficult situations.

<http://sibs.org.uk/>

13. Parents with disabilities

<http://www.bestbeginnings.org.uk/parents-with-disabilities>

14. Supporting CDKL5

www.supporting-cdkl5.co.uk

15. Bringing us together

Bringing us together is an online community where family members, carers, young people and anyone interested in disability and/or additional educational needs can share advice, information, news and personal experiences.

<http://bringingustogether.org.uk/>

16. Sensory Stories and Postural Care

We have been working with Jo Grace from the Sensory Story Project to develop a series of three self-resourced stories. They have been written with the view to supporting the introduction of supine lying with both adults and children. For further information about Jo and her fabulous work including a free download about how to share a sensory story please visit <http://jo.element42.org/sensory-story-project> They can be shared as bed time stories or during the day time to support and inspire people to practice using supine lying.

Here are some little tasters:

Beauty Sleeps - We all know the story of Sleeping Beauty, and if you want the Beauty in this story to be Sleeping Beauty then she can be that for you; but this story does not have to be read as Sleeping Beauty. We all also know about the need to get our beauty sleep. Multiple beauty sleeps will surely make us all the more beautiful, so this story could be part of a bedtime routine aimed at waking up a little more beautiful each day. The Beauty in the story is clearly loved by the world around her, as plants and animals work together to make her comfortable. Here we can take the word

Beauty to mean more than the thin surface that covers us, this Beauty is one of spirit, she must be beautiful inside for everyone to care about her so much. <http://www.posturalcareskills.com/courses/sensory-stories/beauty-sleeps>

Space – Jo has purposefully chosen the space shuttle for this Sleepy Sensory Story because it is designed to return to Earth. Your adventurer's journey is not one that will last forever, they will be returning to tell you all about it. The flight lasts for the night only, in the morning they return. Waking up is their landing; and perhaps they will return with moon dust between their toes and tales to tell of the brightness of distant suns. <http://www.posturalcareskills.com/courses/sensory-stories/space>

The Beach House - The Beach House is based upon a model of guided meditation intended to help the person being guided to reach a state of deep relaxation. By moving through doorways, gateways and down steps the subconscious mind is led to a relaxed state conducive with sleep.

<http://www.posturalcareskills.com/courses/sensory-stories/the-beach-house>

The stories can be ordered from our website at a cost of £12 each. They come in the form of a book with an introduction, instructions for both resourcing and facilitating the story as well the story itself. We hope very much that you enjoy sharing them!
sarah@posturalcareskills.com

17. Action Against Cruelty: combating cruelty, harassment and abuse against people with learning disabilities

Action Against Cruelty provides practitioners and service users with guidance on tackling cruelty towards people with learning disabilities and towards building supportive and informed communities in which people can live safe, independent and fulfilling lives.

<http://www.lemosandcrane.co.uk/actionagainstcruelty/index.php?id=219636>

18. Stop Learning Disability Hate Crime - One year on

www.stophateuk.org

Main office: 0113 293 5100

info@stophateuk.org

19. Welcome to LD Practice Editor's choice – quarterly roundup of the key articles from Learning Disability Practice

(only subscribers to Learning Disability Practice will be able to access the full articles – everyone else will be able to read the abstract only)

As a busy nursing professional, Editor's choice highlights articles of interest that you may have missed or would like to revisit.

Simply click on any of the following articles to start reading:

[Who chooses to be a nurse, and why?](#)

[Exposure to health inequalities as a measure of outcomes](#)

[Assessing the needs of offenders](#)

[Managing pulmonary aspiration in service users](#)

[Dental services for children with autism spectrum disorder](#)

Colin Parish, Editor
Learning Disability Practice
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- 20. A Potential Diamond.**
<http://apotentialdiamond.org/>
- 21. The four health systems of the United Kingdom: how do they compare?**
<http://www.health.org.uk/publications/the-four-health-systems-of-the-united-kingdom-how-do-they-compare/>
- 22. How is the NHS performing? April 2014 Kings fund**
<http://www.kingsfund.org.uk/publications/how-nhs-performing-april-2014>
- 23. TLAP**
<http://www.thinklocalactpersonal.org.uk/nl/view.cfm?nid=771>
- 24. Webinar for professionals who are introducing personal health budgets to people with learning disabilities**
<http://www.thinklocalactpersonal.org.uk/News/PersonalisationNewsItem/?cid=10080>
- 25. Personal health budget peer leader development programme**
NHS England has given peoplehub a grant to develop a personal health budget peer leader development programme. This programme will enable people with a personal health budget to develop their leadership skills and gain the necessary knowledge to work alongside the NHS England personal health budget regional leads. Regional leads are currently supporting Clinical Commissioning Groups to implement personal health budgets well so this is a fantastic opportunity for personal health budget holders to shape local policy and practice.
- To find out more and make an application, please follow this link
http://www.peoplehub.org.uk/?page_id=842
Please submit your application by Friday 16th May 2014
- 26. Citizenship for All an accessible guide from The Centre for Welfare Reform**
<http://www.keystocitizenship.com/>
- 27. Mental Health Crisis Care Concordat**
Improving outcomes for people experiencing mental health crisis
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/281242/36353_Mental_Health_Crisis_accessible.pdf
- 28. Michael Brown Author - MentalHealthCop blog**
<http://about.me/mentalhealthcop>
- 29. Fetal Alcohol Spectrum Disorders Interdisciplinary perspectives**
<http://www.routledge.com/books/details/9780415670166/>
- 30. Drinking alcohol while pregnant could become a crime after landmark test case**
<http://www.independent.co.uk/life-style/health-and-families/health-news/drinking-alcohol-while-pregnant-could-become-a-crime-after-landmark-test-case-9147417.html>

31. Current general practice nursing workforce (Would be good to get some LD input into this)

The RCGP General Practice Foundation and Practice Nurse Journal are working together to establish baseline information on the current general practice nursing workforce and how well placed it is to meet the challenges of delivering care in the future and training the next generation of practice nurses.

Knowing the facts will help to demonstrate the need for a sustainable budget to develop the GP nursing workforce now and in the future.

Please take a few minutes to complete this short survey - your help is greatly appreciated.

This survey will close 31st April 2014.

<http://www.surveymonkey.com/s/gpnworkforce2014>

